

This is a pre-print of a piece that is forthcoming in the Medical Law Review

COMMENTARY

KINSHIP: BORN AND BRED (BUT ALSO FACILITATED)? A COMMENTARY ON ‘DONOR CONCEPTION: ETHICAL ASPECTS OF INFORMATION SHARING’ (NUFFIELD COUNCIL ON BIOETHICS: LONDON, 2013)

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Keywords: donor conception; human rights; Nuffield Council on Bioethics; rights; right to know; stewardship state

INTRODUCTION

Some questions seem to need no thought at all. Secrecy or openness? Lies or truth? In each instance, one answer seems obvious, the other repellent. More than this, a straight, to-the-point answer seems the only sensible choice. Why complicate the questions? To do so would raise the spectre of the Secret State;¹ it might also stymie moves towards ‘open’ science and give succour to practices of commercial confidentiality that harm life and health.

Other questions, by contrast, seem to need far too much thought. Most of us duck and dodge these, but some cleave to certainties even in the face of paradox, a plurality of views and potentially profound consequences. Family life, as many have pointed out, often throws up questions of this second sort. Take the duo with which we started: ‘secrecy or openness?’ and ‘lies or truth?’ They seemed straightforward questions, but change the context to a family

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¹ See N Whitty, T Murphy and S Livingstone, *Civil Liberties Law: The Human Rights Act Era* (OUP: Oxford, 2000) 329–376.

one—or, more broadly, to kinship—and they register very differently. We may live in ‘the information society’ but how many of us live, or want to live, in an ‘information family’? Also, if kinship is both ‘born and bred’,² how should *different* family truths be handled and who, within what will always be a web of relationships, decides this? Within one, single family there could be truths that are genetic, other truths that are biological (in the sense that they include, but are broader than, genetic truth), others again that are social³ and still others that are a braiding of different truths. Moreover, day-to-day within this family, as in so many families, relationships may be replete with ‘open secrets’, with ‘knowing what not to know’ and ‘knowing about but not talking about’.⁴ ‘Regrets’, ‘second thoughts’ and the like may be commonplace too.

Put shortly, kinning and de-kinning are complex and contested, and questions concerning them tend to be complex and contested too. They are questions with which one has to grapple. However this ‘grappling with’ isn’t just private and personal; very often it takes institutional form too. Family practices have long been a concern of, for example, courts and quasi-courts, and of parliaments too. Today, amidst rising numbers of ART families, bodies charged with ‘public bioethics’ have also been engaging with family practices. One such body is the Nuffield Council on Bioethics (‘the Council’), which is based in London and funded jointly by the Medical Research Council, the Nuffield Foundation and the Wellcome Trust. As many will know, the Council was established in 1991 as an independent body that would examine and report on ethical issues in biology and medicine, and it has—as its website claims—‘achieved an international reputation for advising policy

² J Edwards, *Born and Bred: Idioms of Kinship and New Reproductive Technologies in England* (OUP: Oxford, 2000).

³ Moreover, ‘the biological aspects of kinship are also deeply social insofar as they are given meaning and made more or less significant in different societies’: see Nuffield Council on Bioethics (n 6 below) para 1.17.

⁴ See in particular C Smart, ‘Family Secrets: Law and Understandings of Openness in Everyday Relationships’ (2009) 38 *Journal of Social Policy* 551; C Smart, ‘Law and the Regulation of Family Secrets’ (2010) 24 *International Journal of Law, Policy and the Family* 397.

makers and stimulating debate in bioethics’.⁵ In April 2013 it published a report—‘Donor Conception: Ethical Aspects of Information Sharing’⁶—that, for us, lives up to this reputation. Produced by a small, expert working party in a process involving consultation and fact-finding, the Report considers the impact of the disclosure/non-disclosure of information about genetic origin in families created in the UK through assisted reproduction using donor gametes. In line with its Terms of Reference, the Report pays particular attention to four matters: first, the range of stakeholders involved, the complexity of the relationships between them and the ethical values at stake; second, the quality of the evidence currently available; third, the support available to both donors and donor-conceived families; and finally, the role of law and professional guidance in determining the provision of information, and in intervening in donor-conceived families’ decisions with respect to disclosure.

In this paper, we summarise the Report. We also comment on it. There is, we think, a lot to compliment: from the emphasis on kinship to the strong support for parents as decision-makers, and the characterisation of donor-conception information as both personal and ‘interpersonal’. There is also adroit handling of personal identity, in that the genetic dimension is acknowledged but not allowed to squeeze out other identity-crafting forces. There is an invocation of ‘the stewardship state’⁷ that, to be honest, we find harder to assess. But what interests us most of all is how rights are framed in the Report; we concentrate on this in section III below, where it will be the stepping-off point for a set of comments on bioethics, rights and human rights, and law. We begin however with some background.

⁵ <www.nuffieldbioethics.org/about> (accessed 9 August 2013).

⁶ <www.nuffieldbioethics.org/sites/default/files/Donor_conception_report_2013.pdf> (accessed 9 August 2013) (‘the Report’).

⁷ For the ‘launch’ of this idea, see Nuffield Council on Bioethics, ‘Public Health: Ethical Issues’ (London 2009) <www.nuffieldbioethics.org/sites/default/files/Public%20health%20-%20ethical%20issues.pdf> (accessed 9 August 2013).

I. BACKGROUND

In the UK alone, in the years 1992–2009, almost 36,000 people were born following donor-conception treatment at licensed clinics (accounting for 20 per cent of all births resulting from *in vitro* fertilisation).⁸ Throughout this period, the practice was regulated by the Human Fertilisation and Embryology Act 1990 ('the HFE Act'). That legislation has, of course, been amended on several occasions: one such change concerned the information kept about donors. Originally, section 31(3) of the Act allowed donor-conceived people to apply for non-identifying information about the donor upon reaching the age of 18 (and to facilitate this, donors were asked to provide some information, which could be passed to potential recipients). Mostly however parents were advised not to tell: telling pinpointed the donor-conceived family, and ART families more generally, as 'different'; not telling allowed them to pass as 'ordinary'. On 1 April 2005, with the implementation of the Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004,⁹ the law changed: from that date, licensed clinics were no longer allowed to accept fully-anonymous donation. Today, almost 10 years later, it seems right to ask: have practices changed too? And where does the change in the law fit in that?

The picture is complex. There are, for instance, at least five types of donor-conceived family in the UK today. There are, first, those with a donor-conceived child who was born following treatment in a licensed UK clinic with gametes donated after April 2005: these children are able to obtain identifying information about the donor from a register (the Register of information) maintained by the regulatory body, the Human Fertilisation and

⁸ Human Fertilisation and Embryology Authority (HFEA), 'Donor Conception: Births & Children' (2012) <www.hfea.gov.uk/donor-conception-births.html> (accessed 9 August 2013).

⁹ The Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004 SI 2004/1511.

Embryology Authority (HFEA), once they reach the age of 18 (with non-identifying information available to them from the age of 16). Second, there are families where a child was conceived in the same circumstances but with gametes donated between August 1991 and April 2005: here the HFEA can only supply non-identifying information about the donor—unless the donor chooses to make themselves identifiable, perhaps by ‘re-registering’ with the HFEA. Third, there are families where a child was conceived in a UK clinic with gametes donated before the coming into force of the HFE Act in 1991: the HFEA can offer no information, but there is a voluntary register, now known as the Donor Conceived Register, which might be of use.¹⁰ Clinics may also have some early records of their own. This brings us to the final two in the quintet of family groupings: these are, first, families where a child was conceived following informal (non-clinical) arrangements for sperm donation and, second, those where a child was conceived following cross-border reproductive care (CBRC). These latter conceptions did not take place in licensed clinics in the UK, so there are no details, identifying or otherwise, about the donors in either the HFEA’s Register or any pre-1991 records held by clinics themselves.¹¹

Amidst the differences, however, there is also common ground between these five families: to have knowledge of donor conception requires intentional or accidental disclosure and most donor-conceived individuals in the UK do not know how they were conceived. There is anecdotal evidence, as the Report points out, that an increasing number of parents are telling their children about donor conception.¹² Moreover, more parents are saying they

¹⁰ <www.donorconceivedregister.org.uk> (accessed 9 August 2013).

¹¹ For parents’ experiences, see P Nordqvist, “‘Dealing with Sperm’: Comparing Lesbians’ Clinical and Non-Clinical Donor Conception Processes” (2011) 33 *Sociology of Health and Illness* 114; L Culley and others, ‘Crossing Borders for Fertility Treatment: Motivations, Destinations and Outcomes of UK Fertility Travellers’ (2011) 26 *Human Reproduction* 2373; I Turkmendag, ‘When Sperm Cannot Travel: Experiences of UK Would-Be Parents Seeking Treatment Abroad’ in ML Flear and others (eds), *European Law and New Health Technologies* (OUP: Oxford, 2013) 362.

¹² Report (n 6 above) paras 4.4–4.5.

intend to tell. It also seems that parents are more open if the child was conceived by egg donation (in a recent UK study, 41 per cent of the children conceived by egg donation and 28 per cent of those conceived by sperm donation had been told about donor conception¹³). Still, the evidence base continues to be very limited (especially outside of sperm donation) and there is also very clearly a difference between ‘intending to tell’ and actually doing so¹⁴—not least because, generally speaking, one has to tell not just one’s donor-conceived child but numerous others too.

There are two other, rather clearer trends: one is the increasing use of CBRC by would-be parents who need donor gametes; the other is the child’s ‘right to know’ movement. Would-be parents from the UK report that the main reason they have been going abroad is the shortage of gametes here ‘at home’¹⁵—a problem they associate with the change in the law.¹⁶ There was however a shortage before the removal of anonymity, and opinions differ as to whether it was the change in the law, an inefficient donor-recruitment policy, or both that exacerbated the supply problem. Amidst rising levels of concern, steps have been taken. Permitted levels of compensation for donors have increased¹⁷ and the HFEA has set up a National Donation Strategy Group, which brings together a wide range of experts to develop new approaches to raising awareness of donation. Whether such measures will increase supply, and in turn reduce CBRC, depends in part on the second trend we want to discuss: the child’s ‘right to know’ movement.

¹³ J Readings and others, ‘Secrecy, Disclosure and Everything In-Between: Decisions of Parents of Children Conceived by Donor Insemination, Egg Donation and Surrogacy’ (2011) 22 *Reproductive Biomedicine Online* 485.

¹⁴ For a recent review, see A Indekeu and others, ‘Factors Contributing to Parental Decision-Making in Disclosing Donor Conception: A Systematic Review’, *Human Reproduction Update*, 27 June 2013.

¹⁵ See F Shenfield and others, ‘Cross Border Reproductive Care in Six European Countries’ (2010) 25 *Human Reproduction* 1361; Culley and others (n 11 above).

¹⁶ See Turkmendag (n 11 above).

¹⁷ The change followed a public consultation conducted by the HFEA: see HFEA, ‘A Review of the HFEA’s Sperm and Egg Donation Policies’ (2011) <www.hfea.gov.uk/docs/2011-0113_Donation_review_background.pdf> (accessed 9 August 2013).

There is, to be clear, no *right* to know under UK law. The decision to disclose rests with parents and, as we explain below, the Council believes this should not change. Others, including The Children's Society, the British Association for Adoption and Fostering (BAAF), and the Project Group on Assisted Reproduction, British Association of Social Workers (PROGAR), take the opposite view. Indeed it was a call by The Children's Society for a change in the original HFE Act that prompted the government to launch the consultation that led to the abolition of full anonymity. More recently, PROGAR has been at the forefront of claims-making for further changes to the law. Its view is that donor-conceived children are the major stakeholders: thus, for PROGAR, 'the primary ethical concern is that [as the law stands] the welfare of those who are most likely to be affected, donor conceived offspring, is not afforded paramountcy'.¹⁸ It wants a debate about retrospective disclosure of donors' identity and about a birth registration system that would ensure those who are donor-conceived are alerted to their status and informed about how to retrieve 'their' information. It has also suggested that would-be parents should not be accepted for treatment if they state their intention to withhold information from any child who might be born.

Looked at more broadly, it seems that much of the claims-making for the child's 'right to know' emphasises one, some or all of the following: genetic background will become increasingly important for medical reasons; genealogical knowledge is also central to the development of personal identity; the position of donor-conceived people should be aligned more closely with that of adopted people; and the stigma around donor conception has faded. It is, in many ways, a 'modern' mix: it draws on rights thinking and on genetic

¹⁸ Response to the call for evidence by PROGAR (2012) para 1.1 <<http://www.nuffieldbioethics.org/sites/default/files/files/PROGAR.pdf>> (accessed 9 August 2013).

thinking, and it says that disclosure should not be a ‘life-style choice’¹⁹ for parents. It also sees traces of the donor-conceived child’s ‘right to know’ in the law—in domestic case-law,²⁰ in Strasbourg case-law on both paternity testing and the practice of anonymous birth,²¹ and in provisions of the UN Convention on the Rights of the Child which say that a child should be able to know her or his parents as far as possible.²²

Making rights real, in law and in practice, is however no simple matter. The human rights non-governmental organisations (NGOs) and groups of experts who draw up and publicise sets of principles in particular areas (eg, sexual orientation and gender identity) will testify to how hard it is to turn such ‘soft, soft law’ into law. They will also testify to the ways that rights, even when they have the standing of ‘real’ or ‘hard’ law, generally ebb and flow. Also, even the most strongly-worded rights ‘in principle’ are no guarantees of those rights ‘in practice’. Moreover, as regards the donor-conceived child’s ‘right to know’, *genetic thinking* seems just as complex as rights thinking (and the two are of course related in that, today, both human rights law-makers and claims-makers contribute to genetic thinking). Consider the following: as we noted earlier, the child’s ‘right to know’ movement has sometimes drawn an analogy between donor conception and adoption. Recently however, the arrival of mitochondrial DNA (mDNA) replacement techniques which aim to prevent the transmission of inherited mitochondrial disorders from mother to child,²³ has thrown up a new analogy: is the mDNA donor akin to the gamete donor? Or is there a relevant ‘genetic’ or other difference?

¹⁹ *ibid* para 2.2.

²⁰ *Rose and Another v Secretary of State for Health* [2002] EWHC 1593 (Admin).

²¹ *Mikulić v Croatia* (App no 53176/99) 7 February 2002 (paternity testing); *Odièvre v France* [GC] (App no 42326/98) 2003-III; 38 EHRR 871; *Godelli v Italy* (App no 33783/09) 25 September 2012 (secret or anonymous birth).

²² UN Convention on the Rights of the Child (20 November 1989, entered into force 2 September 1990) 1577 UNTS 3.

²³ UK scientists have pioneered research into variations of IVF procedures which include using part of a donated egg to replace the faulty mitochondria of the affected mother. Any resulting children from the therapy would be born with nuclear DNA from their parents’ sperm and egg, and the egg donor’s mitochondrial DNA.

The new techniques have already been considered by the Council; they have also been the subject of a public consultation by the HFEA. The Council's view is that the donor of mitochondria should not be given the same status in all aspects of regulation as a reproductive egg or embryo donor: for example, mDNA donors should not be mandatorily required to be identifiable to the individuals born from their donation.²⁴ Similarly, in the HFEA's public consultation a majority of participants felt that because the role of mitochondria is limited to energy production, the technique is more akin to 'tissue donation'; that mitochondrial replacement therapy was less likely to impact on a person's physical characteristics or identity; and that the resultant child did not need identifying information about the mitochondrial donor.²⁵ In summary, although both egg donation for reproductive purposes and egg donation for mitochondrial replacement assist procreation, it seems that more social meaning and relational responsibility are ascribed to the former. Accordingly, the resultant child's 'quest for identity' is perceived to be more relevant in egg donation. Because however this judgement is based at least in part on the number of genes that are transferred between the donor and the child's mother, it raises questions about where we are headed with 'genetic thinking'. Why is—and why should—numbers of genes be so significant?

II. THE REPORT

We turn now to the Council's Report. We have already detailed the Terms of Reference: as the Executive Summary points out, the basic task for the Working Party was to 'consider

²⁴ Nuffield Council on Bioethics, 'Novel Techniques for the Prevention of Mitochondrial DNA Disorders: An Ethical Review' (London 2012), paras 5.14 and 5.16
<www.nuffieldbioethics.org/sites/default/files/Novel_techniques_for_the_prevention_of_mitochondrial_DNA_disorders_compressed.pdf> (accessed 9 August 2013).

²⁵ HFEA, 'Mitochondria Replacement Consultation: Advice to Government' (2013), <www.hfea.gov.uk/docs/Mitochondria_replacement_consultation_-_advice_for_Government.pdf> (accessed 9 August 2013).

questions of information sharing in practices of donor conception in the UK'.²⁶ Privacy, openness and access to information were thus the key foci. Crucially, however, this is not a report about such matters in general or in the abstract: context is at its core. Hence 'openness' may be an imperative in today's Euro-American societies, 'geneticisation' may seem to be increasing, and privacy may seem to be at odds with quotidian uses of information and communication technologies, but none of this leads the Council to the conclusion that openness in *donor conception* is 'intrinsically valuable'.²⁷ Instead, the Report says, openness to children about their means of conception is important 'in so far as it contributes to the quality of relationships within the family, and to the well-being both of parents and of donor-conceived people'.²⁸ Put differently, because donor conception is 'first and foremost about *people*',²⁹ and because the 'information' we are talking about here is both personal and 'interpersonal',³⁰ context has to be centre-stage: 'openness may or may not be beneficial, depending on the context.'³¹

The Report recommends no change to the law: UK law should not revert to fully anonymous donation either across the board or as an option; equally, there should be no additional screening of prospective parents in connection with their disclosure intentions, and no registration of donor conception on birth certificates.³² Indeed one of the Report's central conclusions is that: 'when, if and how to disclose should remain a private decision for families to take'.³³ But this conclusion does not stand alone. Evidence may still be patchy, some matters may be unknowable (in particular, the views of those who do not know they are

²⁶ Report (n 6 above) executive summary, para 1.

²⁷ *ibid* para 31.

²⁸ Report (n 6 above) para 5.33.

²⁹ Report (n 6 above) executive summary, para 26.

³⁰ *ibid* para 30.

³¹ *ibid* para 31.

³² Report (n 6 above) para 6.30; executive summary, para 40.

³³ Nuffield Council on Bioethics, 'Summary of report' <www.nuffieldbioethics.org/sites/default/files/DonorConception_recommendations_overview.pdf> (accessed 9 August 2013).

donor-conceived) and studies may suggest that both ‘disclosing’ and ‘non-disclosing’ families do well up to early adolescence, but there is—the Report says—‘sufficient evidence to point to the conclusion that, other things being equal, it will usually be better for children to be told, by their parents and at an early age, that they are donor-conceived’.³⁴ This, the Report goes on to say, means there are responsibilities—notably for parents of donor-conceived children, but also for donors and donor-conceived people (the other parties in the ‘donor-conception triangle’³⁵). Moreover, ‘third parties, including both professionals and the state in its regulatory role, potentially also have responsibilities’.³⁶

So what are these various responsibilities and what implications for regulation flow from them? The Report spends most time on the responsibilities of, on the one hand, parents and, on the other, the state. Parents, it says, have a number of responsibilities, the most important of which is to give ‘careful consideration’ to the disclosure question. This means that, as parents think about their own particular context, they should be willing ‘both to take account of the evidence available, and to engage as necessary with professional support’.³⁷ The state’s bundle of responsibilities stem, the Report claims, from its stewardship role. A stewardship state is a state that *facilitates*—a state that ‘provide[s] conditions, whether physical or social, that help and enable people in making their choices’.³⁸ In the donor conception context, the Report argues, the stewardship state should take steps that are likely to promote the welfare of people affected by donor conception, ‘without unreasonably interfering with the interests of others’.³⁹ Such steps involve trying both to ensure parents are informed as to the best available evidence concerning disclosure and to support parents in

³⁴ Report (n 6 above) para 6.3.

³⁵ Report (n 6 above) Foreword.

³⁶ Report (n 6 above) executive summary, para 35.

³⁷ Report (n 6 above) paras 5.46 and 5.47.

³⁸ Report (n 6 above) executive summary, para 36.

³⁹ *ibid.*

considering this evidence. But the stewardship state should also be taking steps to encourage inclusivity: encouraging, in particular, the acceptance of diversity both in the way people become parents and in the plethora of ways in which they create kin.⁴⁰ This in turn will promote the well-being of those affected by donor conception.

A cluster of recommendations flow from these and other responsibilities outlined in the Report. Some concern medical information: one is that guidance on the screening and assessment of donors with respect to serious, strongly heritable conditions should be reviewed and updated; another is that there needs to be a clear mechanism to allow significant medical information that emerges after donation to be shared between donors and donor-conceived people. Many of the recommendations are addressed to the HFEA. The Report suggests, for instance, that guidance should be issued to licensed clinics setting out what is expected of them with respect to making information from early (pre-1991) records available to donor-conceived adults. Furthermore, the next edition of the HFEA *Code of practice* should explicitly encourage a clinic ethos whereby counselling sessions, offered both at the point of consultation and later, are routine, clear and non-judgemental.⁴¹ Additionally, perhaps by means of a dedicated donor conception website, the Authority should offer factual information about the implications of having treatment with donor gametes outside of licensed clinics.

III. ANALYSIS

There is, for us, a great deal to admire about this Report. There is just one issue—the ‘support, encourage and empower’ (‘SEE’) actions expected of ‘the stewardship state’—on

⁴⁰ Report (n 6 above) paras 5.69–5.71.

⁴¹ *ibid* paras 6.21–6.22.

which we reserve judgement, and one decision—the framing of rights and the boxing-away of them that follows—with which we disagree. To be honest, we don’t know what to make of the ‘SEE-ing’ state. The Report says very clearly that ‘wherever possible, measures that aim to support, encourage and empower those making decisions are preferable (both ethically and practically) to measures that seek to limit or remove choice’.⁴² It also says that the ethos within clinics should be non-judgmental.⁴³ Such comments suggest there is no reason to be concerned about the ‘SEE-ing’ state. Still, care will be needed in practice given that it is the *state* that is, for instance, encouraging past donors to come forward and ‘re-register’ as identifiable donors, or encouraging prospective donors to bring their partners to counselling sessions. Care will also be essential vis-à-vis state engagement with prospective and recipient parents, and more broadly with diverse donor-conceived families. We say this in part because elsewhere measures in practice (notably, US abortion laws that feature information provision and a waiting period) can seem more about ‘force’ than about ‘facilitation’.

If our position on ‘facilitation’ is blurry, we are, by contrast, quite certain that we disagree with the Report’s handling of rights. To be precise: we agree that ‘[m]uch of the contemporary ethical and legal debate on information sharing in donor conception has been phrased in the language of *rights*’ but we would not move from this to the argument that ‘[s]tarting from the language of rights, however, is effectively to start with *conclusions*: the conclusion that particular interests are of sufficient importance to impose duties on others to ensure that the right-holder is able to enjoy the interest in question’.⁴⁴ Nor would we have boxed-away rights in order to consider ‘interests’ and ‘values’ which in turn are weighed and

⁴² Report (n 6 above), executive summary, para 37.

⁴³ *ibid* para 43.

⁴⁴ Report (n 6 above) executive summary, paras 27–28. See further ch 5 of the Report.

balanced and give rise to ‘responsibilities’.⁴⁵ Indeed, as we explain below, what we would like to see is the ‘unboxing’ of rights by the Council and by others too.

To be clear: we are not saying that rights—as law or, more broadly, as a mode of thinking, talking and claims-making—must govern disclosure in donor-conception families, kinship more generally or even report-writing by bioethical bodies such as the Council. It is just that we think it is a mistake to side-line them. The prospect of a mass ‘giving-up’ of rights is remote: recall Duncan Kennedy’s pithy remark, “‘Giving up’ rights would be like a professional athlete giving up steroids when all his or her competitors are still wedded to them’.⁴⁶ True, there is no actual right to know in UK law and there is also a sense from, say, the Children Act 1989 that legally protected rights are not a good way to govern family life, but this is not the same as the ‘giving-up’ of rights. We say this for the simple reason that rights ‘as law’ are never the whole of rights: as Katie Young has emphasised one needs always to consider not just how rights are ‘constitutionalised’ but also how they are ‘constituted’.⁴⁷ What she means is that the *lived details* of rights cannot be known from legal doctrine alone: how rights become law (or not), how they ebb and flow as law, and how their legal form translates into reality—and into personal identity—are part of the detail too. Furthermore, even in terms of rights ‘as law’, if the Conservative party succeeds in its electoral ambition to ‘scrap’ the Human Rights Act 1998, there will still be legally-protected rights—it is only (European) human rights (notably the ECHR) that the party wants to cast aside. It is also worth noting that the party’s views are not shared across the UK: Scotland and Northern Ireland have different relationships with rights and human rights.

⁴⁵ *ibid* paras 28–36.

⁴⁶ D Kennedy, ‘The Critique of Rights in Critical Legal Studies’ in W Brown and J Halley (eds), *Left Legalism/Left Critique* (Duke UP: Durham, NC, 2002) 178, 217.

⁴⁷ KG Young, *Constituting Economic and Social Rights* (OUP: Oxford, 2012).

In sum, rights have different registers, most of which are in flux and few of which are well understood. To explain further, let's begin with the issue to hand: disclosure in donor-conception families in the UK. Currently in this context, rights in what we might call their aspirational or 'claims-making register' seem to be dominated by the child's 'right to know' movement.⁴⁸ But do we know why that is? And might it be attributed in part to a failure to engage with the detail of rights in their 'legal register'—noting, of course, that there is more than one such register (eg, national law, the ECHR, the Convention on the Rights of the Child), and that these registers can and do interact (in part through processes both of 'vernacularisation'⁴⁹ whereby global or European norms are translated to local levels, and of 'aversion'⁵⁰ whereby the non-local is rejected)?

Article 8 ECHR, for instance, is a qualified right, not an absolute one. So why is it that many who speak for, and against, rights as a way of governing family life treat rights as absolutes or 'conclusions'? Furthermore, so far as we are aware there has been no case concerning the *donor-conceived* child's 'right to know' at the European Court of Human Rights ('the Court'). The cases from the Court that do invoke the importance of knowing one's identity concern either paternity testing or the practice of anonymous birth:⁵¹ neither seems akin to donor conception. Moreover in *SH and Others v Austria*, which concerned prohibitions on access to donor conception, the Court expressed the view that Austria's concerns about 'split motherhood' (following from egg donation) add a 'new aspect'⁵² not present in the adoption context. Doesn't this suggest that the Court might not endorse the

⁴⁸ We acknowledge that when would-be parents pursue CBRC, there is also 'silent' claims-making which is, of course, facilitated by EU free movement rights: see Turkmendag (n 11 above).

⁴⁹ SE Merry, *Human Rights and Gender Violence: Translating International Law into Local Justice* (Chicago UP: Chicago, IL, 2006).

⁵⁰ KL Scheppele, 'Aspirational and Aversive Constitutionalism: The Case for Studying Cross National Influence through Negative Models' (2003) 1 *International Journal of Constitutional Law* 296.

⁵¹ See eg the three ECtHR cases cited at n 21 above.

⁵² *SH and Others v Austria* [GC] (App no 57813/00) 3 November 2011, para 105.

analogy between adoptees and donor-conceived people that is popular in claims-making on the ‘right to know’?

More broadly, we think that the paternity testing and anonymous birth cases would repay close reading: in *Odièvre v France*,⁵³ for example, there is both a majority judgment (with a clear delineation of different interests at stake) and a biting dissent.⁵⁴ We also think that any such reading needs to be complemented by an exploration of other cases where the Court has engaged with ART, with ‘genetic thinking’ and, more broadly, with the regulation of new health technologies. How, for instance, does the Court see the capacity and the role of law vis-à-vis such technologies? Recalling say *Evans v UK*,⁵⁵ how does it see ‘second thoughts’ in the reproduction context and how is it configuring genetic, gestational, social and other forms of parenthood? Related to this, to what extent does the Court seem attached to ‘genetic thinking’ vis-à-vis identity and personal development?

Raised eyebrows, even some rolling with laughter, will be the response of many to these suggestions. Why pay attention to a court that wields the ‘margin of appreciation’ (deferring to states as the most appropriate decision-makers) in so many bioethical cases? We see it differently: why not explore if the Court handles all bioethical cases via the margin of appreciation or just some them? Why not look at when it declares a wide margin of appreciation and when, by contrast, it points to an emerging European consensus that could narrow or eliminate that? Furthermore, given what we said earlier about different registers of rights, why not take up the ‘in-practice register’ by exploring what happens in Contracting States after the Court hands down judgment in a bioethical case?

⁵³ *Odièvre v France* [GC] (n 21 above).

⁵⁴ See also *Rose and Another v Secretary of State for Health* (n 20 above) para 61 where Scott Baker J says ‘the fact that Article 8 is engaged is far from saying there is a breach of it’.

⁵⁵ *Evans v United Kingdom* [GC] (App no 6339/05) (2008) 46 EHRR 34.

If the Court is still not an appealing subject, there are plenty of other options that might facilitate the ‘unboxing’ of rights. One very rich possibility is produced by the nexus of rights, law and bioethics. Formulations such as ‘ethics and rights’ (as in UNESCO’s 2005 Universal Declaration on Bioethics and Human Rights), ‘ELSI’ (ethical, legal, and social implications) or ‘ELSEI’ (which adds ‘economic’ to ELSI) are popular today, but what precisely is captured and enacted by such connections and divisions? In similar vein, when Noëlle Lenoir claims ‘Bioethics—it is everything that Europe is about’,⁵⁶ how exactly does ‘bioethical Europe’ relate to ‘legal Europe’, ‘political Europe’ and ‘rights-based Europe’? Another related possibility concerns scientists, scientific societies and science funders. How are rights—as law and as a mode of thinking, talking and claims-making—viewed by these groupings? Do they see them as producing (or as blocking) particular types of science and scientists? To what extent are these groupings active in the ‘vernacularisation’ of rights?⁵⁷ Sheila Jasanoff has argued that Britain’s scientific community sees bioethics ‘first and foremost as a device for safeguarding space for research’:⁵⁸ are rights seen in the same way or differently, and why is that?

CONCLUSION

To summarise: we are not saying the Report is bad (far from it),⁵⁹ or that the Council should become a rights or human rights-based organisation. Nor are we saying that rights or human

⁵⁶ N Lenoir, ‘Biotechnology, Bioethics and Law: Europe’s 21st Century Challenge’ (2006) 69 *Modern Law Review* 1, 1.

⁵⁷ Recall Michael Mulkay’s, *The Embryo Research Debate: Science and the Politics of Reproduction* (CUP: Cambridge, 1997): why not have a similar investigation into the role of scientists in ‘translating’ rights?

⁵⁸ S Jasanoff, *Designs on Nature* (Princeton UP: Princeton, NJ, 2005) 187.

⁵⁹ We accept, in addition, that public bioethics is ‘a much more contingent process than academic work’, see J Montgomery, ‘Reflections on the Nature of “Public Ethics”’ (2013) 22 *Cambridge Quarterly of Healthcare Ethics* 9.

rights should be the premier regulatory, or rhetorical, mode for families, donor-conceived or otherwise. What we *are* saying is that rights and human rights—as law and as form of talking, thinking and claims-making—should not be boxed away. It is true that, within rights thinking, there are absolutes (crucial ones such as the right not to be tortured) but not all rights take this form in the law. Moreover, as we have explained, there is more to rights than rights ‘as law’. We know, of course, that socio-legal scholars have long been concerned about the hype or ‘myth’ of rights; that they have branded rights-based litigation as ‘the hollow hope’.⁶⁰ The ‘have nots’, to use Marc Galanter’s phrase, generally have less success with rights than the ‘haves’: relatedly, they have less access to rights and are less likely to rely on them.⁶¹ Rights have also been linked to the ‘demoralisation’ of medicine⁶² and, more broadly, to the stifling of care, civility and solidarity in the quest for ‘choice’. We, however, prefer Martha Minow’s view: ‘Rights can be understood as a kind of communal discourse that reconfirms the difficult commitment to live together even while engaging in conflicts and struggles’.⁶³ We don’t believe the Council, bioethicists, health lawyers and others have to adhere to the position put forward by Ian Kennedy and Andrew Grubb: namely, that medical law is best seen as ‘a subset of human rights law’.⁶⁴ But we do believe there should be more engagement both with human rights law and with rights and human rights in their non-law modes.

⁶⁰ G Rosenberg, *The Hollow Hope: Can Courts Bring About Social Change?*, 2nd edn (Chicago UP: Chicago, IL, 2008).

⁶¹ M Galanter, ‘Why The ‘Haves’ Come Out Ahead: Speculations on the Limits of Legal Change’ (1974) 9 *Law & Society Review* 95.

⁶² J Montgomery, ‘Law and the Demoralisation of Medicine’ (2006) 26 *Legal Studies* 185.

⁶³ M Minow, ‘Interpreting Rights: An Essay for Robert Cover’ (1987) 96 *Yale Law Journal* 1860, 1910–11. See also T Murphy, *Health and Human Rights* (Hart Publishing: Oxford, 2013); SA Scheingold, *The Politics of Rights: Lawyers, Public Policy, and Political Change* (Michigan UP: Ann Arbor, 2005).

⁶⁴ I Kennedy and A Grubb, *Medical Law: Text and Materials* 2nd edn (Butterworths: London, 1994) 3.